



Spina Bifida

WHAT IS THE PUBLIC HEALTH ISSUE?

Spina bifida is the most common permanently disabling birth defect in the United States. It is considered to be the most complex birth defect that is compatible with human life, affecting 70,000 men, women, adolescents and children across the nation. Spina bifida occurs when the spine of the fetus fails to close during the first month of pregnancy and a complex set of reactions are set into motion that affect the formation of the brain and the central nervous system. Complete or partial paralysis, hydrocephalus, bladder and bowel control difficulties, learning disabilities, depression, latex allergy, and psychosocial issues are some of the conditions which affect those who live with spina bifida. These individuals endure life-long multiple conditions that compromise their health and quality of life. Spina bifida also affects the families who face the daily struggles and uncertainties of their loved ones.

Managing one's health is key to becoming self-sufficient, maintaining independence, and enjoying full participation in society. The Americans with Disabilities Act articulates goals for equal opportunity, full participation, independent living, and economic self-sufficiency. Fulfilling these goals for individuals with spina bifida, requires strategies for health promotion, preventing secondary conditions, and adequately preparing persons with disabilities to understand and monitor their health.

WHAT HAS CDC ACCOMPLISHED?

CDC's National Spina Bifida Program, a collaborative effort between NCBDDD and the Spina Bifida Association of America, aims to find the answers to improve the quality of healthcare and the quality of life for men, women, adolescents and children who live with spina bifida. These efforts are based on the national research agenda for spina bifida which resulted from a conference "Evidence-Based Practice in Spina Bifida: Developing a Research Agenda" held in Washington in 2003.

- The University of Washington has initiated two research projects: 1) to examine the use of assistive devices and the incidence of secondary conditions among adolescents and young adults, and 2) to increase understanding of issues related to health care and the most effective model of health care delivery.
- Indiana University/Purdue University- Indianapolis has initiated research to examine the occurrence of secondary conditions and factors associated with the development of secondary conditions.
- The University of Arkansas has initiated research to determine the prevalence of secondary conditions experienced by individuals with spina bifida in Arkansas.
- The Metropolitan Atlanta Congenital Defects Program will determine the prevalence of different age groups surviving with spina bifida in Atlanta.
- The California Birth Defects Monitoring Program is conducting research to investigate the underlying mechanisms by which folic acid contributes to reduced risks for spina bifida.
- The National Center on Birth Defects and Developmental Disabilities is working with the Department of Veterans' Affairs to determine patterns of treatment and the accumulation of diagnoses for those individuals with spina bifida who are beneficiaries of the Agent Orange Benefits Act.
- The National Spina Bifida Information and Resource Center (SBAA) aims to prevent the recurrence of pregnancies affected by neural tube defects, expand local programs via state spina bifida associations, promote research projects, and expand information resources for those with spina bifida.

WHAT ARE THE NEXT STEPS?

- Continue supporting research efforts to reduce secondary conditions, to maintain functional independence, and to improve overall quality of life for individuals with spina bifida.
- Identify additional research topics to continue this effort.

For information on this and other CDC and ATSDR programs, visit www.cdc.gov/programs.

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